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Bereavement support standards and bereavement care pathway for quality palliative care provision

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Abstract

Objective: Provision of bereavement support is an essential component of palliative care service delivery. While bereavement support is integral to palliative care, it is typically insufficiently resourced, under researched and not systematically applied. Our aim was to develop bereavement standards to assist palliative care services to provide targeted support to family carers.

Method: Mixed methods study including: (1) literature review; (2) survey of palliative care service providers in Australia; (3) interviews with national (Australian) and international experts (4) key stakeholder workshops and (5) a modified Delphi – type survey.

Results: Ten standards were developed along with a pragmatic care pathway to assist palliative care services with implementation of the standards.

Significance of results: The bereavement standards and care pathway are a key initiative in the evolution of bereavement support provided by palliative care services. Future endeavours should refine and examine the impact of these standards. Additional research is required to enhance systematic approaches to quality bereavement care.

Keywords: Bereavement, palliative care, family care givers, standards, guidelines.

Introduction

Provision of bereavement support is an essential component of palliative care service delivery, which is explicitly acknowledged in several seminal national and international publications (National Institute for Clinical Excellence (NICE) 2004; World Health Organization 2004; National Consensus Project 2009; De Lima, Bennett et al., 2012). While bereavement support is integral to palliative care, it is typically insufficiently resourced, under researched and not systematically applied (Hudson, 2013; Lynes et al., 2014; Guldin et al., 2015; Stroebe & Boerner 2015; Waller, 2016). It may therefore be considered ‘the forgotten child’ within the palliative care family.

Traditional views of bereavement are being challenged in contemporary thanatology (Neimeyer, 2014). Grief following bereavement is not a psychiatric disorder but a normal emotional reaction to loss (Stroebe & Boerner, 2015). However, whilst loss and grief are fundamental to human life, the course and consequences of bereavement will vary for each individual. For highly resilient individuals, acute grief may be limited to a few weeks and for most people their grief subsides over time (Bonanno & Kaltman, 2001).

For a subgroup of individuals, around 10-15%, the symptoms of distress following the death of a family member or friend are more intense and persistent (Prigerson et al., 1996; Latham & Prigerson, 2004). Known variously as Complicated Grief (Prigerson et al., 1996) (Shear et al., 2011) or Prolonged Grief Disorder (Boelen & Prigerson, 2007), this condition can be associated with severe mental and physical health problems such as insomnia, substance misuse, depression, depressed immune function, hypertension, cardiac problems, cancer, suicide, work and social impairment. Bereaved individuals in this cohort report higher use of medical services and more frequent hospitalisation than people with similar losses whose grief is less intense and of shorter duration. These effects have been observed for as long as 4 to 9 years after the death (Neimeyer & Burke, 2012).

Neimeyer & Burke (2012), in a summary of the clinical literature on pre-loss risk factors for the development of complicated grief, identified a range of key risk factors which are outlined in Box 1.

[INSERT BOX 1]

In the palliative care setting, bereaved persons have frequently undertaken care-giving roles that can have both positive and negative features, with caregivers prone to physical and psychological morbidity, financial disadvantage and social isolation (Hudson et al., 2011). Depression rates of between 12 - 59% (Hudson et al., 2011) and anxiety rates of between 30–50% have been reported (Grunfeld et al., 2004; Hudson et al., 2011). Alarming, almost half of family carers (n = 300) in one study (Hudson et al., 2013) met the criteria for psychological distress when measured at commencement of palliative care provision.

For all bereaved individuals, grief is experienced in the context of their ‘whole being’, including their physical, emotional, cognitive, behavioural and spiritual manifestations. When grief is complicated and prolonged, evidence suggests that intervention is both indicated and effective (Currier et al., 2008). However providing universal bereavement services is unnecessary and offering therapy to resilient individuals is known to be of limited utility (Schut & Stroebe 2005; Wittouck et al., 2011).

Therefore, targeting scarce resources for people who will benefit most is important. A tiered or layered approach to bereavement care has been advocated based on meta-analyses of clinical trials (Schut & Stroebe, 2005). However, there appears to be a dearth of contemporary practice standards that explicitly articulate what resources palliative care services should allocate, when they should allocate them, how and by whom. Findings from the US and Australia indicate that bereavement co-ordinators and counsellors are not available in the majority of hospice or palliative care services, bereavement support is highly variable and there is insufficient evidence based guidance (Demmer 2003; Mather et al., 2008). Another study highlighted that less than 5% of the palliative care budget is directed to bereavement services (Breen & O'Connor, 2007). Recent data from Europe also indicates a lack of guidance on bereavement support and a reliance on intuition over evidence when responding to bereavement care needs in palliative care (Guldin et al., 2015). Alarming almost one-fifth of palliative care services provided no bereavement support (Guldin et al., 2015). Furthermore, services may not formally recognize family carers as ‘clients’ consequently bereavement support needs for

many may go unmet.

Given this background we developed bereavement support standards to assist palliative care services to provide targeted support to family caregivers. The bereavement support standards were developed for use in all Victorian (Australia) adult, specialist palliative care services including community, inpatient, acute and consultancy services. They were also designed for potential application to international palliative care services.

Development process

These standards were developed using five phases of data collection. Ethical approval was obtained from the institution's committee. A summary of the data collection methods and main results relevant to informing the content of the standards are outlined below. A comprehensive project report is also accessible via www.centreforpallcare.org.

Phase 1 Scoping review of international evidence based on systematic reviews, seminal reports and guidelines (for example (Australian Centre for Grief and Bereavement 2001; National Institute for Health and Clinical Excellence 2011; Hudson et al., 2012; Bereavement Services Association and Cruse Bereavement Care 2013; Waller, 2016)) conducted in the last ten years. As part of this process PubMed data bases were utilised to search for systematic reviews and guidelines related to bereavement care . The research team reviewed titles and abstracts for those deemed relevant to the palliative care setting. Key reports referenced in the aforementioned were then sourced and reviewed by the research team; those that were considered 'seminal' had a robust developmental process.

Some selective salient findings from this review to assist in the content of the standards included:

- Whilst it is important to try to identify the group of people who are most likely to develop complicated bereavement and therefore benefit from specialist bereavement interventions, the research regarding the most appropriate responses is not conclusive. There is insufficient empirical

evidence to definitely support the validity of one particular tool to screen for risk of poor bereavement outcome prior to the person's death (Sealey et al., 2015).

- Further work is required to explore strategies to promote resilience, which includes factors and mechanisms that impact on an individual's level of protection against adversities. Resilience is not only a result of an individual's personal attributes but can be impacted by a variety of community and cultural factors. Key attributes of resilient individuals (Boerner & Mancini, 2013) are outlined in Box 2.
- Given the variability in the adaptation to bereavement, it is difficult to make safe predictions in terms of longer term functioning of bereaved individuals before a minimum of six months post-death. At this point, tools such as the PG-13 (Prigerson & Vanderwerken, 2008; Prigerson & Maciejewski, 2012) have been found to have effective predictive validity and reliability for identifying a prolonged and complicated grief disorder.

Pre-bereavement levels of psychological distress are predictive of post-bereavement maladjustment (Stroebe & Boerner, 2015); pre-existing conditions seem to be most important in explaining the occurrence of complicated grief (Bruinsma et al., 2015).

- In relation to actually predicting which family caregivers will meet the criteria for prolonged grief disorder (PGD) (as opposed to those reporting high levels of PGD symptoms) at 13 months post death, the pre death PGD symptoms appear to be a strong predictor (Thomas et al., 2014).
- Further research into the components and meanings of 'anticipatory grief' and how these may affect bereavement adaptation is required (Stroebe & Boerner, 2015).
- More sophisticated methods to screen and then target interventions are required; along with exploring patterns of resilience versus risk (Stroebe & Boerner, 2015).
- Therapy is effective in mitigating the suffering of 'at risk' groups suffering traumatic loss (e.g. bereavement following the death of a child or violent death), and is particularly efficacious when it is offered to those persons with clinically significant symptomatology (Kissane et al., 2006).

A variety of experiential, cognitive-behavioral, and narrative methods are being developed, showing promising results in the treatment of bereavement-related distress (Neimeyer, 2014).

- A systematic review of grief counselling interventions highlighted that many studies had methodological limitations but recommended that Complicated Grief Therapy (Shear et al., 2005) and Family Focused Grief Therapy (Kissane et al. 2006) show potential as effective interventions that warrant further empirical investigation (Waller, 2016).
- Meeting the needs of bereaved persons with complicated grief can be seen as a complex, specialized task requiring input from suitability trained staff (Guldin, et al., 2015).
- Provision of bereavement support for culturally and linguistically diverse groups is a priority (Arthur et al., 2011).

[INSERT BOX 2]

Phase 2 Survey of all publicly funded Victorian palliative care services (in patient and home care).

The survey was developed by the project team and sought to obtain a descriptive overview of bereavement provision. It was sent to the manager of all Victorian palliative care services (in patient and home care) . Questions (mixture of open and closed) focussed on overviews of the bereavement services offered including by whom and to whom. Palliative care services were also asked about the ways in which family carers were screened for risk and their key challenges and priorities related to bereavement care . The survey was completed by 46 of 60 palliative care services, a response rate of 77%. The majority of palliative care services were using some form of formal or informal bereavement risk assessment and were offering some sort of bereavement support to clients although there was little consistency regarding the assessment tools being used, staff training and who was offered bereavement support. The cumulative results of this survey also highlighted the variability of resources for the provision of bereavement support within a palliative care context.

Phase 3 A first draft of the standards was prepared by the research team based on phase one and two and presented to an project advisory group for feedback and refinement. The expert advisory group was selected in partnership with the Department of Health and comprised: Department of Health (Victoria, Australia) palliative care department representative; bereavement counsellor; consumer representative; and an interstate bereavement academic. Selection of these advisors was sought via the

Department of Health (Victoria, Australia) palliative care department. The advisory group highlighted that standards be adapted to concentrate more explicitly on the following three areas:

1. Strategies for screening and assessment for psychosocial distress and risk of complicated.
2. Clarity and direction around training requirements and roles of staff and volunteers were required.
3. Clarity regarding the specific expectations of palliative care bereavement services.

Phase 4 The next draft of the bereavement standards were presented at two workshops and then refined. The first workshop (n =22) comprised a range of multidisciplinary palliative care and bereavement health professionals, academics and service managers from rural, regional and metropolitan palliative care services. A second workshop (n= 17) was convened by Palliative Care Victoria (the peak body for palliative care) comprising members of its psychosocial, spiritual, bereavement special interest group.

Phase 5 The penultimate draft of the standards was circulated via an electronic survey to a group of expert Australian (n= 8) and international (n=4) bereavement experts (selected by the project advisory committee). The purpose of this approach using a modified Delphi technique was to gain consensus about the specific content, applicability and evidence underpinning the standards. Only one round of review was required as all participants confirmed the credibility of the standards and agreed that all key information was included.

The bereavement support standards for palliative care services

These standards are recommended as a minimum level of bereavement support to be provided to primary carers and bereaved individuals by specialist palliative care services. This section outlines each of the standards: the criteria for meeting the standards are outlined in the final report (Hall et al., 2012). The guiding principles underpinning these standards are conveyed in Box 3.

More detail about factors to consider when implementing the standards at different points in the bereavement trajectory are contained in the bereavement care pathway (see Table 1).

[INSERT BOX 3]

Standard 1: Access

All primary carers of clients cared for by a specialist palliative care service are eligible to access palliative care bereavement services regardless of age, gender, culture, sexual orientation, socio-economic status, religious beliefs, physical or other disability or ability to pay.

Standard 2: Coordination of bereavement services

Bereavement programs in palliative care services should provide coordinated services.

Standard 3: Training and support

All staff in a palliative care service, including administrative staff, will come into contact with bereaved people and will therefore require training and support in dealing with bereaved individuals.

Staff and volunteers who have contact with bereaved individuals are required to achieve appropriate competencies in delivering bereavement support.

Standard 4: Screening and assessment

Screening and assessment for the presence of psychosocial and spiritual distress and risk of complicated grief is a continuous process undertaken from the time the client enters the palliative care service to many months after the client's death (where pertinent). These assessments are multidisciplinary and interdisciplinary as clients may disclose different information to different staff at different times.

Pre-death screening and assessment

- Several tools are recommended for screening for psychosocial distress such as the Distress Thermometer (National Comprehensive Cancer Network, 2013), the General Health Questionnaire (McCabe et al., 1996; Goldberg et al., 1997). The PG-13 (Prigerson & Vanderwerken, 2008;

Prigerson & Maciejewski, 2012) has been found to have effective predictive validity and reliability for identifying problematic bereavement experiences.

Where pertinent the screening should be followed up with a comprehensive holistic assessment and/or referral to a suitably qualified professional. However, there is insufficient empirical evidence to support the validity of one particular tool to screen for risk of complicated bereavement prior to the person's death. For this reason, in addition to the use of a tool, a structured assessment should be undertaken through a conversational exploration of risk factors and strength/resilience factors as outlined earlier.

Post-death screening and assessment

Due to the variability in the adaptation to bereavement it is difficult to make safe predictions in terms of longer term functioning of bereaved individuals before a minimum of six months post-death. There are several different tools available to screen for risk (Sealey et al., 2015), tools such as the PG-13 (Prigerson & Maciejewski, 2012) appear to have predictive validity and reliability for identifying a prolonged and complicated grief disorder.

Standard 5: Bereavement support strategies

The recommended bereavement supports include two types of strategies:

- (1) Universal strategies that are targeted at all carers and bereaved individuals.
- (2) Specialist bereavement support strategies targeted at those with elevated risk of developing prolonged or complicated grief or with current psychosocial and/or spiritual distress.

Universal strategies include:

- (a) Screening and risk assessment as detailed in Standard 4.
- (b) Best-practice symptom management of the terminally ill client to reduce the impact of traumatic death on carers as well as the client themselves.

(c) Provision of structured information and support at various points along the grief trajectory including:

- At admission to the palliative care service.
- When death is imminent.
- Immediately following the death.
- At regular intervals following the death such as three, six and around 12 months (and beyond if appropriate).

(d) Provision of access to support strategies such as:

- Participation in a bereavement information session and opportunities to review and reflect on the experience of loss.
- Activity based programs such as walking, meditation, music and art groups.

Specialist bereavement support strategies may include:

Bereavement counselling and psychotherapy using evidence informed specialist interventions for complicated grief such as:

- Cognitive Behavioural Therapy (CBT) for complicated grief (Boelen et al., 2006)
- Focused Family Grief Therapy (Kissane & Bloch, 2002)
- Complicated Grief Treatment (Shear et al., 2005)
- Meaning reconstruction approaches to grief therapy (Neimeyer, 2000)
- Online support (Wagner, 2009)
- Bereavement support groups.

In general, the more complicated the grief process, the greater the efficacy of specialist bereavement interventions. The empirical evidence underpinning these interventions should be explored comprehensively prior to implementation.

Standard 6: Clinical handover and referral to specialist services

Where provision of bereavement support falls outside the skills and competencies of palliative care staff, referral to external specialist agencies or practitioners is undertaken.

Standard 7: Community education and health promotion

The importance of promoting community awareness of bereavement issues and acceptance of the bereaved is recognized and acted upon. Information regarding grief and bereavement is available for General Practitioners, employers and other groups.

Standard 8: Privacy, confidentiality and consent

The palliative care bereavement program ensures the privacy and confidentiality of its bereaved clients.

Standard 9: Integration with the health and support system

The bereavement support program is part of a general health and support system working to promote the health and wellbeing of bereaved individuals and the wider community.

Standard 10: Resource allocation

Resources are allocated in a systematic manner that allows the palliative care service's bereavement program to respond to the changing needs of clients and staff.

Bereavement support care pathway

Table 1 outlines recommendations for implementation of the standards along the grief trajectory. Whilst all of the standards apply at each point on the grief trajectory, the table highlights where a specific standard applies to different actions along the bereavement support pathway.

[INSERT TABLE 1]

Formal endorsement and Implementation

The final version of the standards was formally endorsed by the Victorian Department of Health's Palliative Care Clinical Network, which provides clinical leadership in the implementation of policy directions and program initiatives in Victoria.

A series of training workshops were subsequently conducted throughout Victoria for palliative care service providers. These offered information about the theoretical rationale for the standards, an update on contemporary bereavement research, an opportunity to apply the standards to clinical examples and to develop services develop an implementation strategy. Pre and post questionnaires (developed by the project team) were administered to the multidisciplinary attendees (n = 21). In addition to significant improvements in participants' knowledge of the Bereavement Support Standards improvements were also observed in their knowledge of the underpinning theoretical and clinical rationale for the standards, their knowledge of support strategies across three levels of need and their progress in identifying implementation strategies a number of other positive outcomes were identified. Participants valued the opportunity to meet together and to work methodically through the standards and their implications for practice.

Following an audit of palliative care services conducted by the Victorian State Auditor (Victorian Government, 2015) the Auditor advocated that these bereavement standards be utilized to screen individuals at risk of complicated grief and provide appropriate bereavement support. As a result of this the Department of Health is exploring the use of the standards as performance measures for palliative care agencies.

Discussion

A key measure of quality palliative care should be the well-being of family carers in the years after relinquishing the role (Hudson, 2013) . Accordingly, bereavement support should be targeted, evidence based and systematically applied. However the development of bereavement services has lagged behind other palliative care initiatives (Morris & Block, 2015) and scientific inquiry into meeting the needs of bereaved family caregivers has received insufficient attention (Stroebe &

Boerner, 2015). Given the inconsistency in the delivery of bereavement services by palliative care teams, we set out to develop standards for the provision of bereavement support to be utilized by palliative care services via a multi stage process incorporating best available evidence and expert opinion. The standards were augmented with the development of a bereavement care pathway.

There were several limitations with the standards. They were not specifically targeted at culturally and linguistically diverse populations or at children and other groups with special needs. Caring for the needs of these groups may require enhanced knowledge, skills and strategies that are not detailed in these standards but are, none-the-less, critical for the provision of best-practice bereavement care. Future attention also needs to be given to how to address the needs of people who have elevated distress but are not part of the small percentage of people who meet the criteria for PGD or have severe complications of grief . Whilst the standards were underpinned by systematic reviews of the literature a formal evaluation of the levels of evidence was not undertaken. We did explore the impact of training health care professionals to implement the standards however we acknowledge the sample size was relatively small; hence we recommend subsequent research is needed to more comprehensively explore benefits of training in order to foster successful uptake and implementation.

Given these limitations we advocate that implementation of the standards should be coupled with a comprehensive evaluation and we welcome subsequent empirical investigation of the impact of the standards in terms of clinical, resource and service delivery outcomes. Direct involvement with bereaved carers is essential in the evolution of evidence based bereavement support. We must dismiss the myth that we need to wait for several months before approaching caregivers for potential research involvement; data is emerging that family caregivers are willing to be approached sooner rather than later after the death of their relative (Bentley & O'Connor, 2015) and they can gain rewards from research participation (Hudson, 2004).

The public health model of bereavement support whereby the bereaved are categorized into three groups (high, moderate and low risk) (Aoun et al., 2015) makes conceptual sense. However, more empirical data is needed to support this approach. The process for determining the scope of a

bereavement service has recently been advocated by Morris and Block (2015) and this appears to be a useful guide. It is also vital that future initiatives focus on attempting to minimize the propensity for prolonged grief.

High level evidence shows that preparing family caregivers for the role of supporting a person with advanced disease has valuable psychological and social sequelae including lessening the propensity for distress during bereavement (Hudson et al., 2015). This preparation can comprise components such as: the typical role of being a caregiver, how to support the person with advanced disease, self care, support services and considerations for impending death and bereavement. These preventative approaches seem to have merit and more systematic approaches to implementation of such initiatives are warranted.

Developments in bereavement theory are beginning to change our understanding of what constitutes a common response to loss and, by association, our view of what constitutes pathological grief. This shift toward a refined understanding of the heterogeneity of the grief response is particularly important for how we discern who may need more formalized therapeutic intervention (Neimeyer, 2014). Post traumatic stress disorder, anxiety and depression (for example) have long been included in the Diagnostic Statistical Manual (Stroebe & Boerner, 2015) while Persistent Complex Bereavement Disorder is considered a condition for further study. Service providers need to be clear about what they should screen for and what is the priority for formal therapeutic intervention(s).

Conclusion

While the birth of the modern hospice and palliative care movement is approximately half a century old, unfortunately the bereavement support score card reveals a ‘fail’. Bereavement support is supposedly core to palliative care yet the rhetoric is not matched by the reality. Bereavement care; with seemingly few exceptions, is haphazard, under-resourced and lacking a sound evidence base. The standards and care pathway described herewith are an attempt to help progress the bereavement care agenda; they are not perfect, and we advocate further refinement and testing. Other initiatives,

including more research activity (Waller, 2016), are beginning to surface; so that with sustained and collective efforts, the landscape of bereavement support will show significant signs of improvement.

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References

- Aoun, S. M., Breen, L.J., Howting, D.A., Rumbold, B., McNamara, B., Hegney, D. (2015). Who Needs Bereavement Support? A Population Based Survey of Bereavement Risk and Support Need. *PloS One*, 10(3).
- Australian Centre for Grief and Bereavement (2001). *Minimum standards for bereavement support programs in Palliative Care Services in Victoria*. Melbourne, Australian Centre for Grief and Bereavement. Available from <https://www.grief.org.au>
- Bentley, B. & O'Connor, M. (2015). Conducting research interviews with bereaved family carers: when do we ask? *Journal of Palliative Medicine*, 18 (3), 241-245.
- Bereavement Services Association and Cruse Bereavement Care (2013). *Bereavement Care Service Standards*. United Kingdom. Available from <http://www.cruse.org.uk/>
- Boelen, P. & Prigerson, H. (2007). The influence of prolonged grief disorder, depression and anxiety on quality of life among bereaved individuals: A prospective study. *European Archives of Psychiatry and Clinical Neuroscience*, (257), 444-452.
- Boelen, P. A., Van Den Hout, M. A., & Van Den Bout. (2006). A Cognitive-Behavioral Conceptualization of Complicated Grief. *Clinical Psychology: Science and Practice*, 13(2), 109-128.
- Boerner, K. & Mancini, A. D. (2013). On the nature and prevalence of uncomplicated and complicated patterns of grief. *Complicated Grief: Scientific Foundations for Health Care Professionals*. London, Routledge: 55-67.
- Bonanno, G. A. & Kaltman, S. (2001). The varieties of grief experience. *Clinical Psychology Review*, 21(5), 705-734.
- Breen, L. J. & O'Connor, M. (2007). The fundamental paradox in the grief literature: a critical reflection. *Omega: Journal of Death and Dying*, 55(3), 199-218.
- Bruinsma, S.M., Tiemeier, H.W., Heemst J.V, van der Heide A, Rietjens, J.A. (2015). Risk Factors for Complicated Grief in Older Adults. *Journal of Palliative Medicine*, 18(5), 438-446.
- Currier, J. M., Neimeyer, R. A. & Berman J. S. (2008). The effectiveness of psychotherapeutic interventions for bereaved persons: a comprehensive quantitative review. *Psychological Bulletin*, 134(5), 648.
- De Lima L., Bennett, M.I., Murray, S.A., Hudson, P., Doyle, D., Bruera, E., Granda-Cameron, C., Strasser, F., Downing, J., Wenk R. (2012). International Association for Hospice and Palliative Care (IAHPC) List of Essential Practices in Palliative Care. *Journal of Pain and Palliative Care Pharmacotherapy*, 26(2), 118-122.
- Demmer, C. (2003). A national survey of hospice bereavement services. *OMEGA-Journal of Death and Dying*, 47(4), 327-341.
- Goldberg, D.P., Gater, R., Sartorius, N., Ustun, T.B., Piccinelli, M., Gureje, O., Rutter, C. (1997). The validity of two versions of the GHQ in the WHO study of mental illness in general health care. *Psychological Medicine*, 27(1), 191-197.

Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C.C., Willan, A., Viola, R., Coristine, M., Janz T. (2004). Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*, 170(12): 1795-1801.

Guldin, M-B., Murphy, I., Keegan, O., Monroe, B., Lacaste Reverte, M., Benkel, I. (2015). Bereavement Care Provision: A Survey by the EAPC Bereavement Care Taskforce. *European Journal of Palliative Care*, 22(4).

Hall, C., Hudson, P. & Boughey, A. (2012). Bereavement support standards for specialist palliative care services. Melbourne, Victoria: Australia, Department of Health. Available from [http://centreforpallcare.org/assets/uploads/Bereavement%20support%20standards\(1\).pdf](http://centreforpallcare.org/assets/uploads/Bereavement%20support%20standards(1).pdf)

Hudson, P. (2004). Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing*, 10(2), 58-65; discussion 65.

Hudson, P. (2013). Improving Support for Family Carers: Key Implications for Research, Policy and Practice. *Palliative Medicine*, 27(7), 581-582.

Hudson, P., Remedios, C., Zordan, R., Thomas, K., Clifton, D., Crewdson, M., Hall, C., Trauer, T., Bolleter, A., Clarke, D et al. (2012). Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients. *Journal of Palliative Medicine*, 15(6), 696-702.

Hudson, P., Thomas, K., Trauer, T., Remedios, C., Clarke, D. (2011). Psychological and Social Profile of Family Caregivers on Commencement of Palliative Care. *Journal of Pain and Symptom Management*, 41(3), 522-534.

Hudson, P., Trauer, T., Kelly, B., O'Connor, M., Thomas, T., Summers, M., Zordan, R., White V. (2015). Reducing the Psychological Distress of Family Caregivers of Home Based Palliative Care Patients: Longer Term Effects from a Randomised Controlled Trial. *Psycho-Oncology*, 24(1), 19-24.

Kissane, D. & Bloch, S. (2002). Family Focused Grief Therapy. *Bereavement Care*, 22(1), 6-8.

Kissane, D.W., McKenzie, M., Block, S., Moskowitz, C., McKenzie, D.P., O'Neill, I. (2006). Family Focused Grief Therapy: A Randomized, Controlled Trial in Palliative Care and Bereavement. *American Journal of Psychiatry*, 163(7), 1208-1218.

Latham, A. E. & Prigerson, H. G. (2004). Suicidality and Bereavement: Complicated Grief as Psychiatric Disorder Presenting Greatest Risk for Suicidality. *Suicide and Life-Threatening Behavior*, 34(4), 350-362.

Lynes. C., Phillips, J., Keane, C., Sloan, D., Berger, A. (2014). An Evaluation of a Bereavement Program in a US Research Hospital. *American Journal of Hospice and Palliative Medicine*, 33(2),150-3.

Mather, M.A., Good, P.D., Cavenagh, J.D., Ravenscroft, P.J. (2008). Survey of Bereavement Support provided by Australian Palliative Care Services. *Medical Journal of Australia*, 188(4), 228-230.

McCabe, C.J., Thomas, K.J., Brazier, J.E., Coleman, P. (1996). Measuring the mental health status of a population: a comparison of the GHQ-12 and the SF-36 (MHI-5). *British Journal of Psychiatry*, 169(4), 516-521.

Morris, S. E. & Block S. D. (2015). Adding Value to Palliative Care Services: The Development of an Institutional Bereavement Program. *Journal of Palliative Medicine*, 18(11), 915-22.

National Comprehensive Cancer Network (2013). NCCN Clinical Practice Guidelines in Oncology (NCCN guidelines): Distress Management. United Kingdom. Available from <https://www.nccn.org/professionals/default.aspx>

National Consensus Project (2009). Clinical Practice Guidelines for Quality Palliative Care, Second Edition. Pittsburgh, Pennsylvania. United States. Available from http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf

National Institute for Clinical Excellence (NICE) (2004). Guidance on cancer services: Improving supportive and palliative care for adults with cancer. The Manual. London, United Kingdom, National Institute for Clinical Excellence: 209. Available from <https://www.nice.org.uk/guidance/csg4>

National Institute for Health and Clinical Excellence (2011). Quality Standard for End of Life Care for Adults. United Kingdom. Available from <https://www.nice.org.uk/guidance/qs13/documents/qs13-end-of-life-care-for-adults-quality-standard-large-print-version2>

Northern Ireland Health & Social Care Services Strategy for Bereavement Care.(2009) Northern Ireland Department of Health, Social Services and Public Safety. Available from <https://www.health-ni.gov.uk/publications/northern-ireland-bereavement-strategy-2009>

Neimeyer, R. A. (2000). Searching for the Meaning of Meaning: Grief Therapy and the Process of Reconstruction. *Death Studies*, 24, 541-558.

Neimeyer, R. A. (2014). The Changing Face of Grief: Contemporary Directions in Theory, Research, and Practice. *Progress in Palliative Care*, 22(3), 125-130.

Neimeyer, R. A. & Burke L. A. (2012). Complicated Grief and the End-of-Life: Risk factors and Treatment Considerations. *Counseling Clients Near the End-of-Life*. New York: Springer.

Prigerson, H., Horowitz, M., Jacobs, S., Parkes, C., Aslan, M., Goodkin, K., Raphael, B., Marwit, S., Wortman, G., Neimeyer, R et al (2009). Prolonged Grief Disorder: Psychometric Validation of Criteria Proposed for DSM-V and ICD-11. *PLoS Medicine*, 6(8), e1000121.

Prigerson, H. & Maciejewski, M. L. (2012). The Inventory of Complicated Grief. *Dana-Farber Cancer Institute Center for Psychooncology & Palliative Care Research*: 13.

Prigerson, H. & Vanderwerken, C. (2008). A Case for the Inclusion of Prolonged Grief Disorder in DSM-V. *American Psychological Association*, xiv, 658.

Prigerson, H.G., Bierhals, A.J., Kasl, S.V., Reynolds, C.F., Shear, M.K., Newsom, J.T., Jacobs, S. (1996). Complicated Grief as a Disorder Distinct from Bereavement-Related Depression and Anxiety: a Replication Study. *American Journal of Psychiatry*, 153(11), 1484-1486.

Schut, H. & Stroebe, M. S. (2005). Interventions to enhance adaptation to bereavement. *Journal of Palliative Medicine*, 8(1), S140-S147.

Sealey, M., Breen, L. J., O'Connor, M., & S. M. Aoun. (2015). A Scoping Review of Bereavement Risk Assessment Measures: Implications for Palliative Care. *Palliative Medicine*, 29(7), 577-89.

Shear, K., Frank, E., Houck, P.R., Reynolds, C.F. (2005). Treatment of Complicated Grief: A Randomized Controlled Trial. *Journal of the American Medical Association*, 293(21), 2601-2608.

Shear, M.K., Simon, N., Wall, M., Zisook, S., Neimeyer, R., Duan, N., Reynolds, C., Lebowitz, B., Sung, S., Ghesquiere, A et al: (2011). Complicated grief and related bereavement issues for DSM-5. *Depression and Anxiety*, 28(2), 103-117.

Stroebe, M. & Boerner, K. (2015). Caregiving and Bereavement Research: Bridges over the gap. *Palliative Medicine*, 29(7), 574-576.

Arthur, A., Wilson, E., James, M., Stanton, W., Seymour J. (2011). Bereavement care services: a synthesis of the literature. The University of Nottingham, London, UK, Department of Health. Available from:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215799/dh_123810.pdf

Thomas, K., Hudson, P., Trauer, T., Remedios, C., Clarke, D. (2014). Risk factors for developing prolonged grief during bereavement in family carers of cancer patients in palliative care: a longitudinal study. *Journal of Pain Symptom Management*, 47(3), 531-541.

Victorian Government, Australia (2015). Victorian Auditor-General's Report on Palliative Care. Victoria, Australia. Available from www.audit.vic.gov.au/publications/...Palliative-care/20150415-Palliative-care.pdf

Wagner, B. (2009). Internet-Based Interventions for Complicated Grief. *Grief Matters: The Australian Journal of Grief and Bereavement*, 44-47.

Waller, A., Mansfield, E., Clark, K., Hobden, B., Sanson-Fisher, R. (2016).Assisting the Bereaved: A Systematic Review of the Evidence for Grief Counselling. *Palliative Medicine*, 30(2), 132-148.

Wittouck. C., Van Autreve, S., De Jaegere, E., Portzky, G., van Heeringen, K. (2011). The prevention and treatment of complicated grief: A meta-analysis. *Clinical Psychology Review*, 31(1), 69-78.

World Health Organization (2004). Cancer Pain Release. 17(1 & 2), 12. Available from www.who.int/cancer/publications/